

THE LEGISLATIVE BLUE RIBBON COMMISSION ON AUTISM

A COMPREHENSIVE SERVICE SYSTEM FOR ADULTS WITH AUTISM SPECTRUM DISORDERS

Youth Transitions into Adulthood

From age three to 22, California children and youth with autism and autism spectrum disorders (ASD) may receive educational/behavioral interventions and services through special education programs offered by local education agencies (LEAs). At age 23, persons are no longer entitled to receive special education services, although adults with ASD may continue to have needs for services and supports throughout their lifetimes. Adults with ASD may have needs for housing, employment, income, personal care, transportation, and other assistance in the basic tasks of daily life.

Federal and state special education laws require LEAs to help prepare pupils with disabilities, including youth with autism, for the transition from school into employment, post-school education, independent living, and community participation. Transition planning is a mandated component of the individualized education plan (IEP) process for special education students. This planning is intended to identify the individual's goals for the future and the services and supports available in the community to help the person meet those goals.

Observers working in the field report that some youth with ASD do not receive adequate transition planning, and planning does not begin at an early enough age. Education professionals may not provide sufficient attention to transition and may not be knowledgeable about services and supports available for persons with disabilities in the community. Observers advocate that transition planning should reflect a multidisciplinary approach with collaboration across the systems, state and local agencies, and providers that serve persons with disabilities.

A multidisciplinary approach to transition planning could help to better identify and address any gaps in the types and amount of services and supports currently available for youth and adults with ASD. It is not clear whether services and supports available to persons with developmental disabilities are as effective as they could be in meeting the unique needs of persons with ASD, particularly adults. This is an important question given the population with autism is aging, and there will be more adults with autism in need of services.

The State's Role in Serving Adults with Autism Spectrum Disorders

In California, the Lanterman Developmental Disabilities Services Act (Lanterman Act) and related laws define the obligations of the state and the California Department of Developmental Services (DDS) to provide services and supports to persons with developmental disabilities and the rights of those individuals.¹ The laws give the individual and his or her parent, guardian, or conservator a leadership role in making decisions that affect his or her life and increasing opportunities to self-direct their services. The laws require that services be available to enable the individual to approximate the pattern of living available to persons without disabilities of the

same age. The laws support the integration of persons with developmental disabilities into mainstream life in their homes and communities.

Under the Lanterman Act, the 21 not-for-profit regional centers that contract with DDS coordinate and purchase services and supports for Californians with developmental disabilities living in the community. Regional centers are the primary source of care coordination and services for adult Californians with developmental disabilities, including autism. Other state and local entities that are responsible for providing health, educational, and social services to Californians may also serve adults with ASD.

Regional Center Services

Persons are eligible for services if they have a substantial developmental disability. State law defines autism as one of the disabilities that make a person eligible for services; mental retardation, epilepsy, cerebral palsy, and conditions similar to mental retardation are other diagnoses that render a person eligible for services. Persons diagnosed with some forms of ASD such as Asperger's syndrome and Pervasive Developmental Disorder Not Otherwise Specified (PDD, NOS) are eligible only if they have impairments that constitute a substantial disability, which is defined by California Code of Regulations Title 17 to be impairments in three of the seven areas of major life activity. Eligibility for persons with Asperger's syndrome and PDD, NOS is determined based on the person's functional ability. It is not clear how many persons with some forms of ASD are not receiving DDS/regional center services. One study estimates that about 20-25 percent of Californians with ASD are not served through DDS and the regional centers.²

Each consumer served by the regional centers has an individual program plan (IPP) that guides the purchase of services. Services may include care coordination, assessment and diagnosis, residential services, vocational services, day programs, respite, transportation, advocacy, and other services that support activities of daily living over a person's lifetime. With some limited exceptions where there is a family share of cost for certain services, services are provided at no charge using federal and state funds. Regional centers are required to pursue generic resources provided by other public agencies and health insurance coverage when they are available and to provide services in the most cost efficient manner.

About 31,000 Californians with autism are currently served through DDS at a cost of over \$210 million per year.³ DDS reports that another 3,000 persons with autism are added to the regional center caseload each year.⁴ Adults with autism age 22 and older (about 4,900 persons) currently represent only about 16 percent of the autism population served by DDS. Children with autism age three to 21 make up nearly 84 percent of the autism population served (55 percent are between age three and nine, 38 percent are between age 10 and 17, and seven percent are between age 18 and 21).⁵ As the autism population ages, there will be increased demand for residential, employment, and other regional center services for adults.⁶ It appears that many youth with autism will begin aging out of the school system in roughly five years. DDS reports that the costs of services as currently delivered to this growing segment of the developmentally disabled population are projected to double in six years, triple in eight years, and quadruple in 10 years.⁷

Residential and Employment Services

Adults with autism may generate greater demand for out-of-home residential placements. Adults with autism are less likely than children to live in their parents' homes. In 2002 the percentage of persons with autism living with their parents was 97 percent for persons younger than age 15, 75 percent for those age 15 to 29, 32 percent for those age 30 to 44, and 15 percent for persons age 45 and older.⁸ Adults with autism may access independent and supported living services to help them live in homes they own or lease in the community. They may also live in 24-hour nonmedical community care facilities licensed by the state Department of Social Services, DDS-operated developmental centers, and 24-hour intermediate care facilities that are health facilities licensed by the state Department of Health Services. Increased needs for housing and service providers to operate facilities are anticipated.

There may also be increased demand for employment services and supports. Regional centers fund habilitation services for adults with developmental disabilities that are no longer in school, have chosen paid work, are not capable of competitive employment, and would not benefit from vocational rehabilitation services offered to persons with disabilities through the state Department of Rehabilitation because the person's disability is too severe. Habilitation services funded through regional centers include work activity programs (WAP) and supported employment programs (SEP). WAP services are provided at work activity centers and persons are paid according to productive capacity. WAP services are intended to promote development of physical capacities, psychomotor skills, work habits, health and safety practices, and other work-related skills. SEP services are specialized services provided in an integrated work setting, such as direct supervision and training (or job coaching) and ongoing post-employment services, in order to help the person attain and retain community integrated employment.

On average it costs DDS more to serve an adult with autism than a child with autism or an adult with a different developmental disability. In 2003-04 the average annual cost of services for an adult with autism was about \$30,000 for persons age 22 to 41, \$35,000 for those age 42 to 61, and \$36,000 for those ages 62 and older. In comparison, the average annual cost of services for a person age 22 and older who was not diagnosed with autism was no more than \$20,000.⁹ In addition, the average cost of services for an adult with autism was 254 percent higher than the cost for a child with autism. Further data analysis is needed to explain the cost differences; however, adults' use of out-of-home residential placements is likely a contributing factor to higher costs for adults.

Some observers report that the quantity and quality of services purchased by regional centers can be limited by funding constraints, reimbursement levels for service providers, and a shortage of workers and high attrition among workers. Regional centers may approve and pay parents to become service providers.

Department of Rehabilitation Services

Adults with ASD may receive services through the state Department of Rehabilitation (DOR). DOR is responsible for assisting Californians with disabilities to obtain and retain employment and maximize their ability to live independently in their communities. DOR provides vocational

rehabilitation services to Californians with all types of disabilities through over 100 offices statewide. Services include employment counseling training and education, mobility and transportation aids, and job search and placement assistance. Consumers of the regional centers may receive DOR services rather than habilitation services through the regional center if DOR services are determined to be appropriate for the individual.

DOR also administers an independent living program that provides technical assistance and financial support for 29 independent living centers (ILCs) and the State Independent Living Council (SILC). SILC prepares a state plan for independent living which sets the policy and funding levels for the ILCs and services. ILCs are community-based, nonprofit agencies designed and operated by individuals with disabilities. All ILCs provide peer counseling, independent living skills training, housing assistance, information and referral, advocacy, and assistive technology. Other services may be provided by individual centers.

Other Major Services

Californians with ASD may also receive services provided by other state and local entities and programs. Some of the major services are identified below.

- Medi-Cal, California's Medicaid Program, provides health care coverage for eligible low-income individuals, including persons with developmental disabilities. Pursuant to a federal Medicaid waiver for home and community-based services, Medi-Cal services may be provided to Californians with developmental disabilities who would otherwise require care in an institution regardless of the parents' or the spouse's income level.
- The In-Home Supportive Services (IHSS) Program, a component of Medi-Cal, provides personal assistance services for eligible individuals, including persons with developmental disabilities so they can remain living in their homes.
- The Supplemental Security Income (SSI) Program is a federal program that provides cash assistance to citizens who are age 65 and older, blind, or disabled. The State Supplementary Payment program (SSP) is a state program that provides additional cash assistance to SSI recipients.
- The state Cash Assistance Program for Immigrants (CAPI) provides cash benefits to aged, blind, and disabled noncitizens (immigrants) who are not eligible for SSI/SSP solely due to their immigrant status. Persons with developmental disabilities may also qualify for other cash, food, housing, and transportation assistance programs that are available to Californians based on financial need and other eligibility criteria.
- Community colleges, trade schools, and other colleges and universities in California may provide education and vocational training to persons with developmental disabilities.
- Intensive, one-on-one job services are available to persons with disabilities and others requiring special assistance through local job centers overseen by the Employment Development Department (EDD). Some persons with disabilities may receive additional

specialized job search, assessment, education and training, placement, and retention services through the Jobs for All (JFA) Program, which is a collaborative effort between EDD and DOR.

Identifying Gaps in State Policy

There may be gaps in state policy related to the provision of comprehensive services to adults with ASD. Consideration may be given to the following issues:

- Adequacy of transition planning by schools, regional centers, and other service systems for youth with ASD transitioning into adulthood;
- Coordination between multiple service systems in an integrated systems approach to serving adults with ASD;
- Effectiveness of current program models for persons with developmental disabilities (i.e., residential, employment, day program, self-directed, and other services) in meeting the unique needs of persons with ASD;
- Availability and accessibility of well-trained service providers for ASD statewide;
- Adequacy of funding to meet the current service needs of adults with ASD and anticipated fiscal impact to the state to meet future needs;
- Eligibility of high-functioning persons with Asperger's syndrome or Pervasive Developmental Disorder Not Otherwise Specified for regional center services; and
- Services that are culturally competent for persons of different racial and ethnic groups.

Endnotes

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- ¹ The Lanterman Developmental Disabilities Services Act and related laws (Divisions 4.1, 4.5, and 4.7 of the Welfare and Institutions Code and Title 14 of the Government Code) are available at <http://www.dds.ca.gov>.
- ² Croen, L., Grether, J., Hoogstrate, J., and Selvin, S. "The Changing Prevalence of Autism in California," *Journal of Autism and Developmental Disorders*, 32(3): 207-215.
- ³ California Department of Developmental Services (DDS), "Table #34, Client Characteristics at the End of June 2006, Autism," Sacramento, California, July 10, 2006, available at http://www.dds.ca.gov/FactsStats/pdf/June06_Quarterly.pdf.
- ⁴ DDS, *November Estimate, Local Assistance for Regional Centers, 2006-07 Governor's Budget*, Sacramento, California, January 10, 2006.
- ⁵ DDS, "Table #34, Client Characteristics at the End of June 2006, Autism."
- ⁶ DDS, *Autistic Spectrum Disorders, Changes in the California Caseload, an Update: 1999 through 2002*, Sacramento, California, April 2003, available at <http://www.dds.ca.gov/autism/pdf/autismreport2003.pdf>.
- ⁷ DDS, *November Estimate, Local Assistance for Regional Centers, 2006-07 Governor's Budget*.
- ⁸ DDS, *Autistic Spectrum Disorders, Changes in the California Caseload, an Update: 1999 through 2002*.
- ⁹ DDS, *Department of Developmental Services Fact Book, Eighth Edition*, Sacramento, California, December 2005, available at <http://www.dds.ca.gov/factsstats/factbook.cfm>.